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Validation of the Symptom Screening in Pediatrics Tool in Children Receiving Cancer Treatments

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Abstract

Background: The objective was to evaluate the reliability and validity of the self-report Symptom Screening in Pediatrics Tool (SSPedi) from the perspective of children with cancer and pediatric hematopoietic stem cell transplant (HSCT) recipients.
Methods: In this multicenter study, respondents were children age eight to 18 years who had cancer or had received HSCT, and their parents. Two different child respondent populations were targeted. More symptomatic respondents were receiving active treatment for cancer, admitted to the hospital, and expected to be in the hospital three days later. Less symptomatic respondents were in maintenance therapy for acute lymphoblastic leukemia or had completed cancer therapy. Children completed SSPedi and then responded to validated self-report measures of mucositis, nausea, pain, and global quality of life. Children in the more symptomatic group repeated SSPedi and a global symptom change scale three days later. Parent proxy-report was optional. Reliability was evaluated using intraclass correlations while convergent validity was evaluated using Spearman correlations.
Results: Of 502 children enrolled, 302 were in the more symptomatic group and 200 were in the less symptomatic group. Intraclass correlation coefficients were 0.88 (95% confidence interval [CI] = 0.82 to 0.92) for test-retest reliability and 0.76 (95% CI = 0.71 to 0.80) for inter-rater reliability. The mean difference in SSPedi scores between more and less symptomatic groups was 7.8 (95% CI = 6.4 to 9.2). SSPedi was responsive to change in global symptoms. All hypothesized relationships among measures were observed.
Conclusions: SSPedi is a self-report symptom bother tool for children with cancer and HSCT recipients that is reliable, valid, and responsive to change. SSPedi can be used for clinical and research purposes. Future work should focus on integration into care delivery.

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More than 80% of children diagnosed with cancer in developed countries can be cured (1), but the consequence of this success includes a high prevalence and intensity of symptoms during treatment (2–4) and chronic health conditions following completion of treatment (5). Active symptom screening is important because children undergoing cancer treatment may not complain and providers may not probe for symptoms (6,7).

We previously identified the need for a symptom screening tool specifically for children receiving cancer treatments (6–8) and thus developed the Symptom Screening in Pediatrics Tool (SSPedi). This prior work included a systematic review of symptom assessment scales and a focus group of pediatric cancer clinicians. The focus group articulated the ideal properties of a symptom bother tool for children with cancer and applied these criteria against the identified instruments. None were considered ideal (6–8). SSPedi asks children with cancer and pediatric hematopoietic stem cell transplant (HSCT) recipients how much 15 symptoms bothered them yesterday or today (7,9,10). SSPedi also allows children to record additional bothersome symptoms not already listed as free text. The initial version of SSPedi was found to be understandable and have content validity after cognitive interviews with 30 children with cancer and 20 parents of pediatric cancer patients (9). We then developed an electronic version of SSPedi with features specifically designed to facilitate child self-report. The electronic version of SSPedi includes an audio feature that reads specific questions or the entire instrument aloud, and a synonym list for each symptom that was primarily derived from children during cognitive interviewing. The app was developed for use on an iPad. When evaluated among 20 children with cancer, all understood the questions and app features of the electronic version (10).

The electronic version of SSPedi was then ready for psychometric evaluation using a multicenter approach. We hypothesized that the final electronic version of SSPedi would demonstrate internal consistency, test-retest and inter-rater reliability, and construct validity (convergent validity, discriminative validity and responsiveness). Thus, the objective of this study was to evaluate the reliability and validity of self-report SSPedi from the perspective of children with cancer and pediatric HSCT recipients.

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Methods

Subjects

Child respondents were a consecutive sample of patients with cancer or HSCT recipients who were age eight to 18 years. Exclusion criteria were illness severity, cognitive disability, or visual impairment that precluded completion of SSPedi, according to the primary health care team. Child respondents had to be able to understand English.

Two different respondent populations were targeted and labeled as the "more symptomatic" and "less symptomatic" groups. The more symptomatic group included eligible children who were receiving active treatment for cancer or undergoing HSCT, admitted to the hospital, and expected to be in the hospital or clinic three days later. Active therapy consisted of any treatment for cancer, including all chemotherapy, radiotherapy, or surgery. This group was expected to have some degree of symptoms, although the amount was expected to vary considerably depending on the reason for admission. Among this group, we anticipated heterogeneity in whether symptoms would improve, worsen, or stay the same three days later. The less symptomatic group included eligible children who met one of the following criteria: 1) nonrelapsed acute lymphoblastic leukemia (ALL) during a routine clinic visit following initiation of at least six months of maintenance chemotherapy and clinically well with no procedure planned that day or 2) in follow-up during a routine clinic visit at least three months after completion of cancer treatment that did not include HSCT and clinically well. When asking the health care team whether the child was clinically well, we asked whether the child had an acute illness such as a cold or worsening of a chronic symptom such as pain. This group was expected to have a lower symptom burden compared with the more symptomatic group.

We also included English-speaking parents or guardians of child respondents for inter-rater reliability assessment. Parent proxy-report was an optional component of the study.

Procedures

Respondents were recruited from nine sites in Canada and the United States (see the "Notes" section). The study received Research Ethics Board approval from the coordinating site (The Hospital for Sick Children) and all other participating sites. Child participants and parents or guardians provided informed consent or assent as appropriate. Demographic information was obtained directly from respondents and from patient health records.

Potential respondents were approached in the inpatient or outpatient setting by a clinical research associate or research nurse. Parents who agreed to participate completed SSPedi on an iPad silently before the child self-reported SSPedi; children did not see their parents' responses. Next, child respondents were invited to self-report SSPedi on the iPad without assistance from parents, although the research assistant or study nurse could answer questions if they arose. Children were encouraged to use the audio and help features if needed. SSPedi consists of the following 15 items: disappointed or sad, scared or worried, cranky or angry, problems thinking, body or face changes, tiredness, mouth sores, headache, other pain, tingling or numbness, throwing up, hunger changes, taste changes, constipation, and diarrhea.

Children then completed a series of self-reported assessments on the iPad for the purpose of construct validation. Instruments consisted of the following: the Children's International Mucositis Evaluation Scale (ChIMES), the Pediatric Nausea Assessment Tool (PeNAT), the Faces Pain Scale–Revised (FPS-R), and a global quality of life (QoL) visual categorical scale. ChIMES is a self-report and proxy-report measure of oral mucositis that is reliable, valid, and sensitive to change (11). ChIMES has two summary scores, the ChIMES Score, which ranges from 0 to 23, and Total ChIMES Percent, which ranges from 0 to 100; higher numbers denote worse mucositis. PeNAT is a reliable and valid measure of present nausea severity in children age four to 18 years (12). It consists of a script that focuses the child on the construct of nausea and a series of four horizontal faces representing increasing nausea severity from "no nausea" to "worst nausea possible." The FPS-R consists of a series of horizontal faces that depict a neutral facial expression of no pain on the left and worst pain on the right. It has six faces and may be scored on a 0–10 scale in which higher numbers denote more pain (13). FPS-R is psychometrically sound and feasible for children age four to 18 years (14). Global QoL visual categorical or analog scales have been widely used in research and are often used to validate other measures (15,16). We used a five-point

Likert scale ranging from 1 = "worst possible" to 5 = "best possible," and thus higher numbers indicate better QoL.

All participating children completed the procedures outlined above on day 1. Children in the less symptomatic group were then finished with the study. Children in the more symptomatic group completed SSPedi a second time 3±1 days later (day 4) for the evaluation of test-retest reliability and responsiveness. In conjunction with the second SSPedi assessment, children self-reported a five-point global symptom change scale (much worse, little worse, same, little better, and much better).

Statistical Analysis

A total unweighted SSPedi score was calculated for each administration. Each item's Likert score ranged from 0 (no bother) to 4 (worst bother); Likert scores were summed for a total score that ranged from 0 (none) to 60 (worst possible). Additional symptoms added as free text were not included in the total SSPedi score.

All threshold criteria for reliability were derived from previously established recommendations (17). To evaluate the test-retest reliability of SSPedi, we included those who reported no change on the global symptom change scale between days 1 and 4 among the more symptomatic group. We calculated the intraclass correlation coefficient (ICC) between the two SSPedi total score assessments, and we anticipated an ICC of 0.75 or greater. To evaluate the inter-rater reliability of SSPedi, we calculated the ICC between children and participating parents or guardians for the day 1 total SSPedi scores, and we anticipated an ICC of 0.6 or greater. A lower ICC was anticipated for inter-rater reliability compared with test-retest reliability because, given the subjective nature of symptoms, the perception of symptoms was expected to differ between children and their parents (18). We also evaluated internal consistency by Cronbach's alpha and anticipated an alpha greater than 0.8 (17).

To evaluate discriminative or known groups construct validity, we hypothesized that mean total SSPedi scores would be statistically significantly higher for children in the more symptomatic group compared with the less symptomatic group. We compared the day 1 total SSPedi scores using the Student *t* test. We examined convergent construct validity by hypothesizing that the following measures would be fairly correlated (Spearman $r \geq 0.25$): the mouth sores SSPedi item and Total ChIMES Percent; the nausea and vomiting SSPedi item and PeNAT; the pain SSPedi item and FPS-R; and total SSPedi score and global QoL. We hypothesized fair correlations because none of the comparisons were exact. For example, mouth sores is one item on the ChIMES mucositis scale, which also includes the ability to eat, drink, and swallow and receipt of pain medication. Similarly, SSPedi separates mouth sores, headache, and other pain (last item used in construct validation) whereas FPS-R incorporates all sources of pain in one scale.

To evaluate the responsiveness of SSPedi, the total SSPedi scores were compared between days 1 and 4 for those in the more symptomatic group who reported symptoms to be much worse or much better on the second assessment. This comparison was conducted using the paired Student *t* test in which changes in SSPedi among those who reported symptoms to be much better were multiplied by –1 (to account for the difference in direction between the worse and better groups).

Finally, in order to evaluate the underlying structure of SSPedi, we performed exploratory and confirmatory factor analysis. The number of dimensions was evaluated using visual inspection of the scree plot.

To calculate the sample size for test-retest reliability of SSPedi, assuming the ICC under the null hypothesis was 0.5 and the ICC under the alternate hypothesis was 0.75, with an α of 0.05 and a β of 0.10, we needed 50 subjects (two-sided) who reported no change in symptoms between the two days (19,20). Assuming that 15% to 20% of subjects would have a second assessment performed and would report no change in symptoms, 300 subjects were required in the more symptomatic group. For known groups validity testing, assuming a minimal clinically important difference of five points (based a priori on clinical opinion), a standard deviation of 15, and an α of 0.05, enrollment of 300 subjects in the more symptomatic group and 200 subjects in the less symptomatic group (10% missing) would provide 93% power. Thus, the total targeted sample size was 300 children in the more symptomatic group and 200 in the less symptomatic group (500 total).

Analyses were conducted using the SAS statistical program (SAS-PC, version 9.4; SAS Institute Inc, Cary, NC). All statistical tests were two-sided, and a *P* value of less than .05 was considered statistically significant.

Results

Between November 11, 2014, and June 5, 2017, 624 children were assessed for eligibility. Of these, 61 did not meet eligibility criteria and 61 declined to participate. Thus, 502 children were enrolled in the study. Figure 1 illustrates the flow of patient identification, enrollment and study participation, and the reasons for exclusion. There were 302 children in the more symptomatic group and 200 in the less symptomatic group. In total, 439 (87.5%) of their parents or guardians were eligible and agreed to provide proxy-report SSPedi scores. Among the 302 more symptomatic children, a day 4 assessment within the prespecified window (±1 day) was obtained in 282 (93.4%). All enrolled participants completed SSPedi and had no difficulty with completion. Although not specifically tracked, younger children were observed to frequently access the audio and help features. Of the 502 child respondents, 46 added free-text comments when asked if any other things had been bothering them lately. Twenty-eight provided further specificity for an SSPedi item (such as location of pain), while 18 provided a non-SSPedi item. The most common non-SSPedi item was itchiness (in four children).

Table 1 shows the demographics of the child and parent participants in the more symptomatic and less symptomatic groups. Overall, 150 (29.9%) enrolled participants were age eight to 10 years, and 308 (61.4%) were male. Leukemia or lymphoma was the most common underlying diagnosis (70.5%), and most child respondents (84.7%) reported English as a first language. Among the more symptomatic group, 32 of 302 (10.6%) were HSCT recipients. Among the less symptomatic group, 64 (32.0%) were children with ALL on maintenance chemotherapy while the remainder had completed cancer treatment. In this group, the median time from diagnosis was 4.4 years (interquartile range = 2.2 to 7.1 years).

Table 2 provides details of SSPedi administration. Total self-report SSPedi scores ranged from 0 to 55 (where 60 is the maximum score possible). The median SSPedi day 1 scores in the more and less symptomatic groups were 12 and 5, respectively. Median time to complete SSPedi was less than three minutes for all respondents in both groups. Among the more

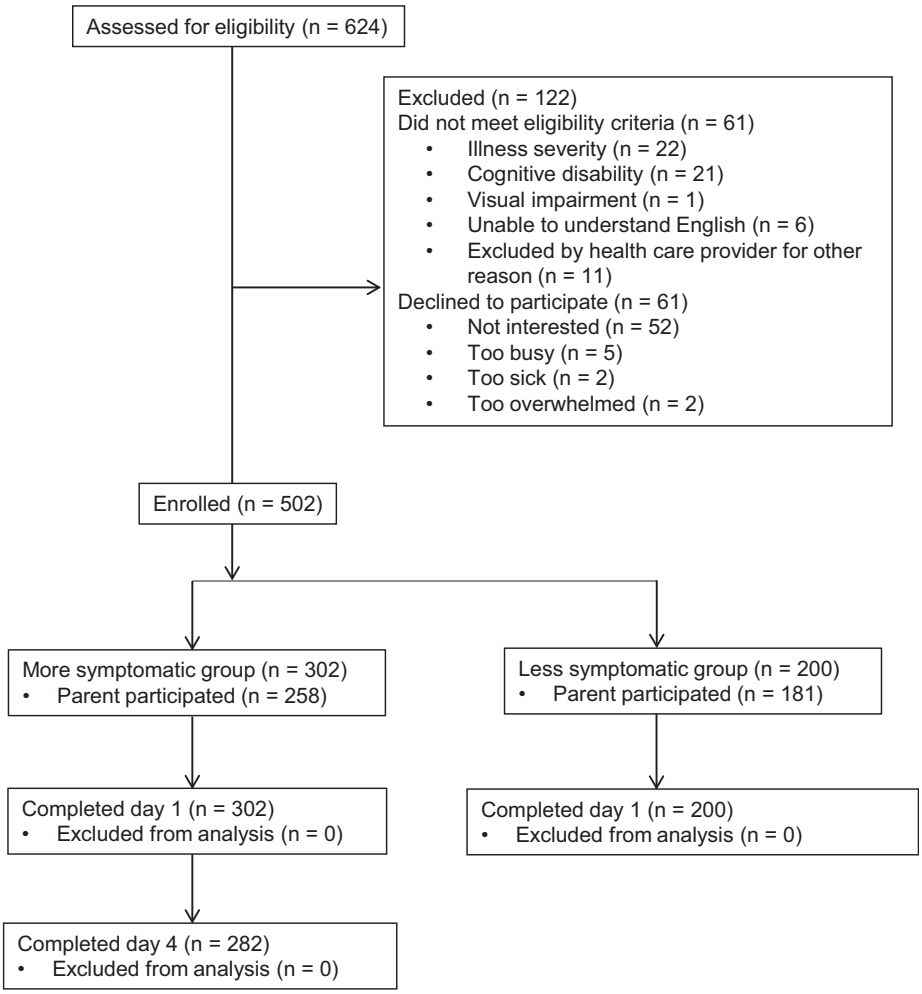

Figure 1. Flow diagram of participant identification, enrollment, and study participation.

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Table 1. Demographics of the study cohort

Characteristic	Total No. (%)	More symptomatic No. (%)	Less symptomatic No. (%)
Child characteristics	(n = 502)	(n = 302)	(n = 200)
Male	308 (61.4)	185 (61.3)	123 (61.5)
Median age (range), y	13.1 (8.0–18.7)	13.2 (8.0–18.5)	13.1 (8.0–18.7)
8–10	150 (29.9)	86 (28.5)	64 (32.0)
11–14	202 (40.2)	128 (42.4)	74 (37.0)
15–18	150 (29.9)	88 (29.1)	62 (31.0)
Diagnosis			
Leukemia/lymphoma	354 (70.5)	181 (59.9)	173 (86.5)
Solid tumor	122 (24.3)	99 (32.8)	23 (11.5)
Brain tumor	18 (3.6)	14 (4.6)	4 (2.0)
Other	8 (1.6)	8 (2.6)	0 (0)
Metastatic disease	96 (19.1)	78 (25.8)	18 (9.0)
Relapse	55 (11.0)	52 (17.2)	3 (1.5)
Stem cell transplantation	32 (6.4)	32 (10.6)	0 (0)
In school	430 (85.7)	233 (77.2)	197 (98.5)
English as first language	425 (84.7)	253 (83.8)	172 (86.0)
Parent characteristics	(n = 439)	(n = 258)	(n = 181)
Male	118 (26.9)	71 (27.5)	47 (26.0)
Median age (range), y	44.5 (19.1–71.7)	44.7 (19.1–69.2)	44.1 (20.1–71.7)
Married	348 (79.3)	209 (81.0)	139 (76.8)
College or university education	323 (73.6)	189 (73.3)	134 (74.0)

Table 2. Characteristics of outcomes

Outcome measures	More symptomatic (n = 302)	Less symptomatic (n = 200)
Symptom Screening in Pediatrics Tool*		
Median total child SSPedi scores day 1 (IQR)	12 (8–19)	5 (2–9)
Mean total child SSPedi scores day 1 (SD)	14.2 (8.8) (n = 282)	6.4 (6.0)
Median total child SSPedi scores day 4 (IQR)	9 (5–15)	NA
Mean total child SSPedi scores day 4 (SD)	11.0 (8.2) (n = 258)	NA (n = 181)
Median total parent SSPedi scores day 1 (IQR)	15 (9–21)	5 (2–10)
Mean total parent SSPedi scores day 1 (SD)	15.5 (8.5)	7.3 (8.2)
Median minutes child complete SSPedi day 1 (IQR)	2.8 (2.2–4.2)	2.4 (1.8–3.2)
Median minutes child complete SSPedi day 4 (IQR)	2.1 (1.6–3.0)	NA
Median minutes parent complete SSPedi day 1 (IQR)	2.9 (2.2–4.4)	2.3 (1.7–3.3)
Children's International Mucositis Evaluation Scale*		
Median ChIMES Scores (IQR)	1 (0–2)	0 (0–0)
Median Total ChIMES Percent (IQR)	4.3 (0–9.1)	0 (0–0)
Pediatric Nausea Assessment Tool, nausea right now, No. (%)		
No nausea at all	202 (66.9)	181 (90.5)
A little bit nauseated	76 (25.2)	18 (9.0)
Even more nauseated	19 (6.3)	1 (0.5)
Nauseated a whole lot	5 (1.7)	0 (0)
Vomited yesterday or today	67 (22.2)	5 (2.5)
Faces Pain Scale–Revised*, median rating (IQR)	0 (0–2)	0 (0–0)
Global Quality of Life Categorical Scale*, median rating (IQR)	4 (3–4)	5 (4–5)
Symptom change rating on day 4 , No. (%)	(n = 282)	NA
Much worse	11 (3.9)	NA
A little worse	57 (20.2)	NA
The same	88 (31.2)	NA
A little better	77 (27.3)	NA
Much better	49 (17.4)	NA

*Scores range as follows: Symptom Screening in Pediatrics Tool 0-60, higher worse; Children's International Mucositis Evaluation Scale (ChIMES) Score 0–23, higher worse; Total ChIMES Percent 0–100, higher worse; Faces Pain Scale–Revised 0–10, higher worse; Global Quality of Life Categorical Rating Scale 1–5, higher better. IQR = interquartile range.

symptomatic group, the global symptom change scale on day 4 was reported as the same (no change in symptoms) in 88 (31.2%) and much better or worse in 60 (21.3%).

Table 3 summarizes the psychometric evaluation results. All reliability and construct validity hypotheses were supported. More specifically, test-retest and inter-rater reliability were excellent, with an ICC of 0.88 (95% confidence interval [CI] = 0.82 to 0.92) for test-retest reliability and an ICC of 0.76 (95% CI = 0.71 to 0.80) for inter-rater reliability. The more symptomatic group total SSPedi scores were statistically significantly higher than the less symptomatic group scores (mean difference = 7.8, 95% CI = 6.4 to 9.2, $P < .001$). When the two groups were compared using the Wilcoxon rank sum test, the two groups remained statistically significantly different ($P < .001$). Those who reported they were much better or worse on the global symptom change scale had statistically significantly changed from their baseline score (mean difference = 5.6, 95% CI = 3.8 to 7.5, $P < .001$). Those who were much better and worse had a mean change of –6.1 and 3.5, respectively. As a sensitivity analysis, we repeated psychometric evaluations among the age eight to ten years cohort, and similar observations were made (Table 3). In the exploratory factor analysis, one factor was suggested to be appropriate by a dropoff in eigenvalues between the first and second factor of 5.23 to 1.34 on the scree plot. Then assuming one factor, confirmatory factor analysis showed an acceptable root mean square error of approximation of 0.076 (21).

Table 4 describes symptoms that were severely bothersome (SSPedi score of 3 or 4) from the perspective of child self-report or parent proxy-report. The SSPedi items "feeling tired" and "feeling more or less hungry than you usually do" were the most commonly cited severely bothersome symptoms.

Discussion

In this multicenter study, we found that SSPedi, a symptom bother tool developed for the purpose of symptom screening in children with cancer and pediatric HSCT recipients, displayed test-retest and inter-rater reliability, construct validity, and responsiveness to change. All children were able to complete SSPedi on an iPad without any difficulties. This work is important because validation of a symptom screening tool is a pivotal step toward improving and maximizing symptom control and QoL.

It is important to emphasize the intended use of this tool, which is clinical utilization as a symptom screening tool. In our previous systematic review, we identified several tools that measure symptoms in children with cancer (6–8), but we felt that none were suitable for this purpose because of their length or content. Thus, SSPedi was designed to be brief and capture the domain most relevant to patients, namely how a symptom bothers or impacts the child. Given its brevity, it is unlikely to be a primary outcome measure in randomized trials, although SSPedi may be useful in observational trials. However, it is

Table 3. Psychometric properties of the Symptom Screening in Pediatrics Tool*

Property	Hypothesis	Total cohort		Age 8–10 years cohort	
		No.	Results	No.	Results
Reliability					
Test-retest reliability	ICC ≥ 0.75 when comparing total SSPedi scores between days 1 and 4 in those who report no change in symptoms	88	ICC = 0.88 (95% CI = 0.82 to 0.92)	30	ICC = 0.91 (95% CI = 0.81 to 0.96)
Inter-rater reliability	ICC ≥ 0.6 when comparing total SSPedi scores between children and parents on day 1	439	ICC = 0.76 (95% CI = 0.71 to 0.80)	150	ICC = 0.76 (95% CI = 0.67 to 0.83)
Internal consistency	Total SSPedi scores Cronbach's alpha ≥ 0.8		Cronbach's alpha		Cronbach's alpha
	Day 1	502	0.86	150	0.83
	Day 4	282	0.86	82	0.83
Construct validity					
Known groups validity	Total SSPedi score higher for more symptomatic vs less symptomatic groups	502	Mean difference = 7.8 (95% CI = 6.4 to 9.2), $P < .001$	150	Mean difference = 6.1 (95% CI = 3.9 to 8.3), $P < .001$
Convergent validity	Mouth soreness SSPedi item fairly correlated with Total ChIMES Percent, $r \geq 0.25$	502	$r = 0.46$ (95% CI = 0.39 to 0.53), $P < .001$	150	$r = 0.37$ (95% CI = 0.23 to 0.50), $P < .001$
Convergent validity	Nausea and vomiting SSPedi item fairly correlated with PeNAT, $r \geq 0.25$	502	$r = 0.48$ (95% CI = 0.41 to 0.55), $P < .001$	150	$r = 0.50$ (95% CI = 0.37 to 0.61), $P < .001$
Convergent validity	Pain SSPedi item fairly correlated with FPS-R, $r \geq 0.25$	502	$r = 0.52$ (95% CI = 0.46 to 0.59), $P < .001$	150	$r = 0.52$ (95% CI = 0.39 to 0.63), $P < .001$
Convergent validity	Total SSPedi score fairly correlated with global QoL scale, $r \leq -0.25$	502	$r = -0.54$ (95% CI = –0.60 to –0.47), $P < .001$	150	$r = -0.50$ (95% CI = –0.61 to –0.37), $P < .001$
Responsiveness	Change in total SSPedi scores for those Much Worse or Much Better on day 4 vs day 1	60	Mean difference = 5.6 (95% CI = 3.8 to 7.5), $P < .001$	21	Mean difference = 2.9 (95% CI = 1.0 to 4.8), $P = .005$

*Statistical tests to calculate two-sided P values were Spearman correlation coefficients for convergent validity, independent Student t test for known groups validity, and independent Student t test for responsiveness. CI = confidence interval; FPS-R = Faces Pain Scale–Revised; ICC = intraclass correlation coefficient; PeNAT = Pediatric Nausea Assessment Tool; QoL = quality of life; SSPedi = Symptom Screening in Pediatrics Tool.

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specifically this brevity that enhances its potential clinical utility.

Dissemination and implementation of SSPedi may improve patient outcomes. In adult oncology, routine patient-reported outcome (PRO) measurement and provision of PRO reports to health care providers improved patient QoL (22–24). Implementation of routine patient self-report symptom screening in adult oncology patients in the province of Ontario improved health outcomes (25), led to decreased emergency room visits, and triggered clinical action for those with higher symptom scores (26,27). Furthermore, a recent randomized trial showed that routine PRO assessment may even improve survival (28). Among participants that were randomized to symptom screening vs standard of care, the median overall survival was 31.2 months (95% CI = 24.5 to 39.6 months) in the symptom screening group vs 26.0 months (95% CI = 22.1 to 30.9 months) in the standard of care group ($P = .03$).

A strength of our study is the development and evaluation of a tool explicitly intended for clinical utilization by children with cancer and pediatric HSCT recipients. SSPedi has elements specifically designed with pediatric use in mind, including the audio and help features. Furthermore, the large number of pediatric patients who participated in this study from multiple institutions improves the generalizability of the study findings to English-speaking North American children.

However, there are limitations of SSPedi. First, it is only available in English. However, translation to other languages is currently in progress. Second, SSPedi is currently only validated for child self-report for children age eight years and older. We are currently developing a version of SSPedi suitable for child self-report for those age four to seven years. A future goal should be to develop and validate a parent proxy-report version of SSPedi for children age seven years and younger. Third, we allowed clinicians to assess acuity of illness and cognitive ability in determining eligibility rather than applying objective criteria. While all included children could complete SSPedi without difficulty, it is possible that clinicians excluded some children capable of reporting symptoms. Fourth is that we had few HSCT recipients and brain tumor survivors, and thus results may not be generalizable to these populations. Fifth, our methodology relied on classical test theory approaches and not newer approaches such as item response theory. Finally, SSPedi lacks the granularity to measure symptom dimensions other than bother.

In conclusion, SSPedi is a self-report symptom bother tool for children with cancer and pediatric HSCT recipients that is reliable, valid, and responsive to change. SSPedi can now be

Table 4. Prevalence of Severe Bother* for SSPedi items for more symptomatic group (n = 302)

SSPedi items	Child day 1 (n = 302) No. (%)	Child day 4 (n = 282) No. (%)	Parent day 1 (n = 258) No. (%)
Feeling disappointed or sad	23 (7.6)	9 (3.2)	47 (18.2)
Feeling scared or worried	22 (7.3)	17 (6.0)	41 (15.9)
Feeling cranky or angry	31 (10.3)	9 (3.2)	30 (11.6)
Problems with thinking or remembering things	15 (5.0)	8 (2.8)	7 (2.7)
Changes in how your body or face look	33 (10.9)	14 (4.9)	27 (10.5)
Feeling tired	99 (32.8)	64 (22.5)	103 (39.9)
Mouth sores	23 (7.6)	12 (4.2)	21 (8.1)
Headache	23 (7.6)	14 (4.9)	15 (5.8)
Hurt or pain (other than headache)	43 (14.2)	26 (9.2)	38 (14.7)
Tingly or numb hands or feet	13 (4.3)	12 (4.2)	5 (1.9)
Throwing up or feeling like you may throw up	40 (13.2)	29 (10.2)	32 (12.4)
Feeling more or less hungry than you usually do	75 (24.8)	41 (14.4)	65 (25.2)
Changes in taste	43 (14.2)	24 (8.5)	47 (18.2)
Constipation (hard to poop)	27 (8.9)	12 (4.2)	37 (14.3)
Diarrhea (watery, runny poop)	30 (9.9)	24 (8.5)	17 (6.6)

*SSPedi score 3 or 4. SSPedi = Symptom Screening in Pediatrics Tool.

used for clinical and research purposes. Future work should focus on translation into other languages and meeting symptom screening needs for children younger than age eight years.

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